



# ***In Support of Caregivers***

*A Publication of the Caregivers' Resource Center and Alzheimer's Support Unit at the Tompkins County Office for the Aging*

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## **“Powerful Tools” Classes Shortened to Ninety Minutes**

This past spring, the *Powerful Tools for Caregivers* classes offered here in Tompkins County were shortened to 1½ hour classes (instead of the 2½ hour classes offered previously). Although the material presented had to be cut back a bit, those in attendance found the format very appealing and we will be continuing to offer 90 minute classes this fall. Of course, this may enable some to attend who were not able to set aside the time to come to the longer classes.

We have listed below the classes that begin in September. Please remember that funds may be available to assist family caregivers who cannot afford to hire substitute care if they cannot leave their loved one alone and there is not another relative or friend to be with them.



We want to make these classes available to all who might benefit from them. In the classes, family caregivers learn to reduce stress, improve self-confidence, better communicate their feelings, balance their lives, increase their ability to make tough decisions and locate helpful resources. The classes are sponsored by a coalition of area agencies and open to those caring for aging relative or friend. They are not intended for professional caregivers. Register by calling the Office for the Aging, 274-5482.

**Mondays, September 19<sup>th</sup> – October 31 (except for October 10): 6 pm – 7:30 pm**  
**Lifelong, 119 W. Court St., Ithaca**

**Tuesdays, September 20- October 25: 10:00 am – 11:30 am**  
**Brookdale Senior Living, 103 Bundy Rd., Ithaca**

## Spring Support Groups

*The Caregivers' Resource Center facilitates the following groups. Call 274-5492 for details.*



### Caregiver Conversations

- Open to those caring for parents or other elderly relatives or friends.  
(Not meeting during the summer months)  
7:00 – 8:30 PM at Lifelong, 119 W. Court St.
- Sponsored in cooperation with Lifelong

### Alzheimer's & Other Dementia Caregiver Support Group

- Open to those caring for loved ones with Alzheimer's or other cognitive impairments
- Meets on the 4<sup>th</sup> Tuesday of each month:  
(July 26, August 23, Sept. 27)
- 1:00 - 2:30 PM in the Office for the Aging Conference Room (320 N. Tioga St., Ithaca)

### Parkinson's Support Group

- Open to Parkinsonians and their Caregivers.
- Meets Quarterly:  
Next Meeting: July 20, 2011
- 2:00 PM - 3:30 PM at Cooperative Extension, 615 Willow Ave., Ithaca
- Sponsored in cooperation with Cornell Cooperative Extension of Tompkins County

### Other Alzheimer's Groups

In addition to the daytime group (above), these meetings may be convenient for some caring for loved ones with Alzheimer's or a related disorder:

**1<sup>st</sup> Wednesday of each month at 5:30 PM**  
at Lifelong, 119 W. Court St., Ithaca. For info., call the Alzheimer's Association at 330-1647.

**3<sup>rd</sup> Wednesday of the Month, 1:00-2:00 PM**  
at Walden Place, Cortlandville. Call 756-8101.

## Local Caregiver Services

### Caregivers' Resource Center & Project CARE Services

#### *Tompkins County Office for the Aging*

David Stoyell, Katrina Schickel, and Marilyn Roberts (274-5482)

*The Caregivers' Resource Center &*

*Alzheimer's Support Unit* offers family caregivers information and consultation services, support groups, workshops, this newsletter, and a lending library of books and videos on caregiving topics. Stop by or call for an appointment.

Volunteers from *Project CARE* give caregivers a needed break and help out in other ways as needed. We may also be able to arrange for paid home care services or short-term respite for stressed caregivers having difficulty paying for those services. Call Katrina to discuss your needs.

### In-Home Counseling & Respite Service

#### *Family and Children's Service*

Jessica Gosa (273-7495)



A caregiver counselor will meet with family caregivers at their home, her office, or elsewhere and help them work through complex caregiving issues or for emotional support. This program also offers grant-funded respite aide service to give caregivers a needed break.

### Adult Day Program

#### *Longview Adult Day Community*

Tuesdays, Wednesdays, Thursdays,  
9 AM- 3 PM

Pamela Nardi (375-6323)



Adult day programs offer older adults companionship along with planned social and recreational activities. It often provides a break from caregiving and time for other matters. Includes lunch and snacks.

# Working with Your Siblings

In a webinar recently produced by the Family Caregiver Alliance, Francine Russo discusses the challenges of siblings cooperating in caring for one or both parents who need ongoing support. She makes the following points:

Families find themselves needing to work together after not having lived together for decades. Old “family rules”



don't work any more and families need to adapt their old roles to new times. It is often hard for families to take a fresh look at the roles each family member played before and might play now.

Some of the problems that can arise:

1. Too many assumptions and not enough communication
2. Family caregivers not asking for what they need.
3. Siblings not knowing what they can give.

Families need to avoid the following traps:

1. Waiting until there is a crisis to talk and/or not including everybody.
2. Siblings thinking that caregiving involves only doing concrete tasks, and if a sister or brother is doing them, that everything is taken care of.
3. Caregivers not really knowing what they want from their siblings. (For example, sometimes a caregiver might need mainly thanks and validation and someone with whom they can vent. Others may need help with tasks.)

4. Falling into the fallacy of “I shouldn't have to ask.”
5. Getting caught up in anger-guilt gridlock. (Making siblings feel guilty doesn't work well. Siblings defend themselves and attack or withdraw.)

It's hard to ask for help. Avoid hints- ask directly. Be specific and be realistic. If one sibling “can't get along with mom,” it doesn't mean he/she can't or won't support their sibling in some way if they learn what might be helpful.

⇒ You can hear Francine Russo speak about these challenges and strategies for working together by watching her webinar (free) that is archived on the website of the Family Caregiver Alliance at [www.caregiver.org](http://www.caregiver.org). (In the webinar section of its home page, click on *Family Caregiving: Work with Your Siblings to Keep Your Life, Family, and Sanity Intact!* ➡.)

⇒ Ms. Russo has also written a book addressing these issues titled *They're Your Parents, Too!: How Siblings Can Survive their Parent's Aging without Driving Each Other Crazy*, Bantam Books, January 2010. This book and others on various family caregiving topics can be borrowing from the Caregivers' Resource Center at the Tompkins County Office for the Aging

⇒ Sometimes a professional from outside the family can help you communicate and mediate conflict. In Tompkins County, two resources are the WiseTalk mediation service of the Community Dispute Resolution Center (273-9347, [www.cdrc.org](http://www.cdrc.org)) and the Caregiver Counseling provided by Family and Children's Service (273-7495).

# LGBT Aging

In 2010, the National Resource Center on LGBT Aging was established through a federal grant from U.S. Department of Health and Human Services. This new Center provides training, technical assistance and educational

**National  
Resource  
Center**



**ON LGBT AGING**

resources to aging providers, LGBT organization, and LGBT older adults (and their caregivers). You can browse resources by subject on its website at [www.lgbtagingcenter.org](http://www.lgbtagingcenter.org). Resources include articles, presentations, videos, and links to publications and local resources in communities throughout the country.

Some of the subjects which may be of interest to family caregivers include: Caregiving, Cultural Competence (of service providers), Elder Abuse, End of Life Decisions, Families, Financial Security, Health & Wellness, Health Care Access, HIV & Aging, Homophobia & Transphobia, Housing, Legal Support, Medicaid & Medicare, Mental Health, Retirement, and Social Isolation.

## Medicaid Spousal Protections

The U.S. Department of Health and Human Services has also recently established a new policy that permits states to extend Medicaid “spousal protection” to domestic partners as well. While nursing home residents must spend down to \$13,800 (in New York) of countable assets before Medicaid will help with their cost of care, their spouses may keep \$74,820 or the amount of their spousal share up to almost \$110,000. If the spouse has low income, he/she may also keep some of the nursing home spouse’s income as well as his/her own up to a total \$2,739 in monthly income. The new HHS policy permits states to extend these provisions to domestic partners, but does not require states to do so. It is important to be aware that these protections primarily help lower-income seniors. For higher

income seniors, the \$110,000 asset figure becomes a floor rather than a protection. Up until now, while non-married seniors may not freely transfer assets to each other under Medicaid rules, the healthy partner has been able to keep all of his or her assets (and has not been expected to contribute to the cost of the nursing home partner’s care). An update will be provided when NY State sets its policy.

## Advance Directives are Important

There are more similarities between LGBT and non-LGBT caregivers than differences—all caregivers provide critically needed support and assistance to older adults to help them age in their communities. However, when compared to their heterosexual counterparts, LGBT older adults are:

- Twice as likely to age as a single person
- Twice as likely to live alone
- Three to four times less likely to have children to support them

While LGBT older adults may not have the same biological family supports as their heterosexual counterparts,



many have developed important social networks of partners, friends, ex-partners, neighbors and others. These networks are often referred to as “families of choice.”

However, LGBT caregivers’ families of choice may not always be recognized under the law. Fortunately, there are legal documents that can protect one’s choices. In New York, these are the “Durable Power of Attorney” and “Health Care Proxy.” For more information on local resources to support both LGBT and non-LGBT caregivers, call the Caregivers’ Resource Center at the Tompkins County Office for the Aging (274-5492).



## Is It Time to Move?

The decision about whether your parents should move is often tricky and emotional. Each family will have its own reasons for wanting (or not wanting) to take such a step. One family may think a move is right because the parents can no longer manage the home. For another family, the need for skilled nursing care motivates a change—often the result of an emergency situation. In some cases, a move frees up cash so that the parent can afford a more suitable location.



## Moving In

In the case of long-distance caregivers, the notion of moving can seem like a solution to the problem of not being close enough to help. For some caregivers, bringing a sick or aging parent to their own home or community can be a viable alternative. Some families decide to have an adult child move back to the parent's home to become the primary caregiver.

## Check home care first

Keep in mind that leaving a home, community and familiar medical care can be very disruptive and difficult for the older parent, especially if they are not enthusiastic about the change. You might first want to explore what services are available in your parent's community to help them continue to live in their home. Look into such services as home health care, a housekeeping service, personal care, home-delivered meals, and transportation services. Check with your parents' friends and doctors, a local social worker, senior centers and other resources in their area and on the Internet for possible sources of help.

## Explore their options

Housing options can be limited by factors such as illness, ability to perform activities of daily living

(for example, eating, bathing, using the toilet, dressing, walking, moving from bed to chair), financial resources and personal preferences. Making a decision that is best for your parent, and making it with your parent, can be difficult. Try to learn as much as you can about possible housing options...

Some families find a conference call is a good way to talk together about the pros and cons of each option. The goal of this call is to come up with a plan that works for everyone, especially your parent....Experts advise families to think carefully before moving an aging adult into an adult child's home. Is there space in your home? Is someone around to help the older person (as needed)? What are your parents able to do for themselves? What personal care are you willing and able to provide—moving your parent from a chair to bed or toilet, changing adult diapers, using a feeding tube, for example? What kinds of home care services are available in your community? What kind of specialized medical care is available nearby?

*Reprinted from the May 2011 issue of Aging  
Arkansas.*

## Liz Simple

An assisted moving service can help with the decision on where to move, what to take with you, assistance with possessions not being moved, help organizing and packing, and managing the details of the move.



***Liz Simple*** is a new assisted moving service in Tompkins County and the Finger Lakes region. To learn more about its services contact Liz Simple at (607) 279-5126, email [lizsimple@gmail.com](mailto:lizsimple@gmail.com), or go online to [www.lizsimple.com](http://www.lizsimple.com).

# Adaptations for Aging Eyes

**J**ulie Ann Nastasi, OTC, OTR/L is an occupational therapist who specializes in low vision rehabilitation. She is on the faculty at Ithaca College. At a recent workshop she addressed some of the common eyes diseases of the elderly (macular degeneration, cataracts, glaucoma and diabetic retinopathy). Of these macular degeneration is the most common.



According to Nastasi, regular vision check-ups by an eye doctor are important because, if a person waits until they experience vision deficits, it is often too late to decrease further vision loss. Occupational therapists and other professionals who specialize in low vision rehabilitation can recommend strategies to help the clients improve their ability to take in and process visual information. They can also suggest environmental adjustments to achieve a better fit between a person with low vision and their surroundings to allow them to function as independently as possible.

These different types of adaptations include lighting (increasing light intensity and avoiding glare) and contrast (black and white is best). Following are some strategies that Ms. Nastasi suggested, organized by room, for modifying the living environment to accommodate someone with low vision:

*(Note: Ms. Nastasi reminds you that a person's physician should be consulted prior to implementing environmental modifications.)*

## Bathroom:

- Use contrasting containers in bath tub
- Use different shaped bottles to identify objects
- Safety awareness with the water (it is hard to see water on surfaces)

- Turn off the water before getting into the tub.
- Dry off before getting out of tub.
- Use contrasting grab bars.

## Toileting:

- Feel for surface to sit on.
- Keep supplies in the same area.
- Use contrast:
  - have the color of the toilet paper contrast against the holder and wall
  - have the toilet seat cover contrast with the floor color.

## Grooming:

- Put toothpaste in a jar.
- Have additional lighting in the room.
- Use magnifying mirrors.
- Organize make-up.
- Put lipstick on finger and then apply to lips.
- Use a system for shaving (left to right) or (right to left)

## Kitchen: Cooking

- Use box mixes.
- Do meal prep over a tray.
- Organize items in the refrigerator and drawers.
- Put electrical tape around the handles of knives.
- Use contrasting materials
- Dip the measuring spoon into the object as opposed to pouring the object onto the spoon.



## Eating

- Again, use contrasting placemats, plates, and utensils.
- Decrease patterns (it's hard to find items on patterned table cloths)
- Describe the position of objects on the plate.

- Finger foods are easier to eat when out with friends.
- Have chef pre-cut meal.
- Keep the fork in the food and cut around the fork.

### Bedroom

- Put extra lighting in the closets
- Use a system to organize clothes.
- Sew buttons in shirts.
- Write down the color of the shoe inside the shoe.
- Keep a flashlight handy.



### Living Room: TV

- When possible use a large screen television.
- Move the chair closer to the TV.
- Use blinds or shades to decrease the glare from windows.
- Make sure electric cords or wires are not loose in the room.
- Remove clutter or hazards in the room.

### Living Room: Reading

- Have good lighting in the room.
- Use spot lighting to increase the amount of light.

- Use lap trays or other positioning devices to position materials appropriately.
- Make sure the user has training in any devices used.

### Telephone

- Put a bump dot on the number 5.
- Program frequently used phone numbers.
- Large print telephones are available.
- Directory assistance is free for the visually impaired with documentation provided by healthcare provider.

### Laundry

- Pin socks together.
- Have different hampers for different colored clothes.
- Put bump dots or high markers on frequently used settings.

*Reprinted with permission from PowerPoint presentation, **Vision and Aging: Common Diagnoses and Adaptations for Aging Eyes**, by Julie Ann Nastasi, OTC, OTR/L, SCLV, Ithaca College Gerontology Institute Series, Spring 2011.*

## Long Distance Support

### What can you do if you live in another city or state?

- ☒ Ask how you can help. Offer ideas if the primary caregiver isn't sure.
- ☒ Offer emotional support. Call and check in regularly. Be someone in whom the caregiver can confide.
- ☒ Offer financial support. Contribute to the household expenses or pay for respite care.
- ☒ Make phone visits. Spend time on the phone visiting with the person being cared for.
- ☒ Give breaks. Take over caregiving duties for a day or weekend each month, or a week every few months. The primary caregiver will look forward to the break.
- ☒ Do those tasks that can be done at a distance. Research the disease or condition or make phone calls to find out about support services.
- ☒ Thank the primary caregiver. Show your appreciation regularly.



## Palliative Care

Palliative care is a medical specialty focused on relieving the suffering experienced by people with serious illnesses. It relieves symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite and difficulty sleeping. It helps the patient gain the strength to carry on with daily life. It improves their ability to tolerate medical treatments and helps them better understand their choices for care.



This comprehensive service is provided by a team of professionals working together with the patient's primary care doctor. Palliative care is not a one-size-fits-all approach to care. The palliative care team looks at the patient as a whole (physical, emotional and spiritual comfort) in order to meet the individual needs of each patient and their family.

Both patients and their families benefit from this medical specialty. Along with symptom management, communication and support for the family are key components of care. The team helps patients and families make medical decisions and choose treatment options. Palliative care is not limited to hospice care. It may be provided at any time during a person's illness, even beginning with diagnosis. It can take place at the same time as curative treatment.

A new study conducted at Massachusetts General Hospital in Boston has found that cancer patients who started palliative care, along with their usual cancer care, soon after their diagnosis lived nearly three months longer than patients given only standard cancer care. To learn more about palliative care or hospice care options in Tompkins County, contact *Hospicare and Palliative Care Services*, 272-0212 or go online to [www.hospicare.org](http://www.hospicare.org)

## Senior Driver Education

Way2Go, a Cornell Cooperative Extension Program provides information on increasing transportation equity and sustainability to Tompkins County residents. Way2Go is also focusing on Senior Driver Education and Retirement, and provides information on other forms of transit in the area, including low-cost or free transportation for medical appointments.

If you, or a family member, are interested in learning more about Senior Driver Education and Retirement, please contact Ray Weaver at (607) 272-2292.

You can also explore various local transportation options on the Way2Go website at [www.Way2Goinfo.org](http://www.Way2Goinfo.org).

Way2Go is sponsoring the following free presentation:

***Retiring from Driving: It isn't the end!***  
**Thursday, June 30 at 1:00 PM or**  
**Thursday, September 15 at 2:30 PM**  
**at Lifelong**  
**119 W. Court St., Ithaca**

Ray Weaver, of Cornell Cooperative Extension, will educate participants about how to approach retiring from driving, and what resources there are in Tompkins County to aid in transportation after driving.



Topics will include medical transportation (in and out of county), transportation for daily tasks (grocery shopping, library, etc.) and beneficial programs offered to help keep seniors active after retiring from driving.

Register by calling Lifelong at 273-1511.



# Alzheimer's Notes

## Unlocking the Silent Prison

An article in the November 21, 2010 issue of Parade Magazine by Christine Wicker recounts some of the ideas of Michelle Bourgeois for communicating with Alzheimer's patients.

Bourgeois is a speech-pathology professor at Ohio State who is an expert at communicating with people who have dementia. "Even when dementia is so advanced that people cannot speak," Bourgeois explains, "they can read if the words are large enough. We know because they smile, make pleasant sounds, and stroke photos of loved ones with captions."



"In contrast, spoken words can go in one ear and out the other. They may understand, but can't store the memory. So they may ask the same question over and over."

A woman at one of Bourgeois' lectures reported that her father would repeatedly ask "Where are we going?" during their weekly drives to the doctor. Bourgeois advised her to answer his questions and also write it down on a notepad and give it to him. When he asked again, she should say (gently), "The answer is in the notepad." When the woman tried this out, she said her dad looked at the notepad, out the window, and back at the notepad. After that, he stopped asking, "Where are we going?"

Similar techniques have helped people cope with anger and anxiety in loved ones with dementia. When a dementia patient got upset at the prospect of taking a shower, Bourgeois suggested to the nursing aid to make a card that read "Showers make me feel fresh and clean" and give it to her after saying it was time to shower. The technique worked.

Bourgeois suggests that family make memory flashcards. "Your mother will never forget you...she just needs help remembering." So one

client told her mom "I have a gift for you" and gave her two photographs. Under one she'd written, "This is my daughter Susan at age three." Under the other was "This is my daughter Susan now." Her mom studied the photos and looked at Susan and said "as beautiful as ever."

## The Great Unlearning

Alzheimer's has been described as "the great unlearning," a "disease of memory," a "demise of consciousness." But what remains when memory unravels? And how might such insights help Alzheimer's sufferers themselves? To hear a fascinating podcast on these matters, from Krista Tippet, host of "Speaking of Faith" on National Public Radio, visit:

<http://being.publicradio.org/programs/2010/alzheimers/>

The radio program was originally broadcast on April 22, 2010. The link will also direct you to other resources (writings, poetry, stories, visuals) reflecting on memory and relationships, absence and loss, and on the frail, tender love between family members.



## Memantine Study

Memantine, a medication approved for patients in advanced stages of Alzheimer's, won't delay the loss of memory and cognitive function that comes in the early stages of Alzheimer's, a new study concludes. Though the drug is prescribed to roughly 1 in 5 patients whose memory loss is still considered mild, those patients progress to dementia just as often, and at the same rate, as those at similar levels of cognitive impairment who take no medications. The study, which reviewed clinical trials that tested memantine's effectiveness for mild cognitive impairment and pooled their results, was published the April 2011 issue of the Archives of Neurology.

# The Caregivers' Resource Center and Alzheimer's Support Unit

**Please call or visit us** at the Tompkins County Office for the Aging in the County Courthouse basement, 320 North Tioga St., Ithaca. Open weekdays, 8:30 AM - 4:30 PM.

**David Stoyell, CRC Coordinator and Newsletter Editor**

**Telephone:** (607) 274-5492

**E-mail:** [dstoyell@tompkins-co.org](mailto:dstoyell@tompkins-co.org)

**Katrina Schickel, Project CARE Coordinator**

**Telephone:** (607) 274-5491

**E-mail:** [kschickel@tompkins-co.org](mailto:kschickel@tompkins-co.org)



## Websites of Interest to Family Caregivers:

**Tompkins County Office for the Aging:** [www.tompkins-co.org/cofa](http://www.tompkins-co.org/cofa)

*(Click on "Gateway to Senior Seniors" at the top of the home page to access our resource guides and back issues of this newsletter.)*

**Family Caregiver Alliance:** [www.caregiver.org](http://www.caregiver.org)

**Next Step in Care:** [www.nextstepincare.org](http://www.nextstepincare.org)

**National Alzheimer's Association:** [www.alz.org](http://www.alz.org)

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